



Smith ScholarWorks

Theses, Dissertations, and Projects

2017

Understanding and negotiating access to preventative sexual health care biotechnology in online communities : a thematic analysis of the Facebook group ""PrEP Facts: rethinking HIV prevention and sex

Dorothy Manley

Follow this and additional works at: <https://scholarworks.smith.edu/theses>



Part of the [Social Work Commons](#)

Recommended Citation

Manley, Dorothy, "Understanding and negotiating access to preventative sexual health care biotechnology in online communities : a thematic analysis of the Facebook group ""PrEP Facts: rethinking HIV prevention and sex" (2017). Masters Thesis, Smith College, Northampton, MA.
<https://scholarworks.smith.edu/theses/1903>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

Dorothy Manley
Understanding and
Negotiating Access to
Preventative Sexual Health
Care Biotechnology in
Online Communities: A
Thematic Analysis of the
Facebook Group “PrEP
Facts: Rethinking HIV
Prevention and Sex”

ABSTRACT

This thesis seeks to understand how access is being negotiated between the U.S. health care system, resources, and institutions by locating conversations about access to Pre-Exposure Prophylaxis (PrEP) within the lay led Facebook group *PrEP Facts: Rethinking HIV Prevention and Sex*. The study offers insight into the fault lines within the health care system and how men who have sex with men (MSM) are managing these fault lines, and providing mentoring and guidance to each other, when seeking access to preventive care. Narratives in the Facebook group illustrate who is accounted for and who falls between the gaps within a medical model claiming universal access to PrEP. The results have the potential to inform the work of health care providers engaged in public health disciplines across professions—from social workers to medical providers.

**UNDERSTANDING AND NEGOTIATING ACCESS TO PREVENTIVE SEXUAL
HEALTH CARE BIOTECHNOLOGY IN ONLINE COMMUNITIES: A
THEMATIC ANALYSIS OF THE FACEBOOK GROUP “PREP FACTS:
RETHINKING HIV PREVENTION AND SEX”**

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

Dorothy Manley

Smith College School for Social Work
Northampton, Massachusetts 01063

2017

ACKNOWLEDGMENTS

This thesis could not have been accomplished without the contributions of many wonderful people for whom I am very grateful.

A very special thanks to my awesome little sister, who is much wiser than me, and who constantly reassured me that I'd be okay and will finish the thesis, who advised me to stop overthinking everything and to buy the hummus sandwich, and who now owes me the pipe that I needed to become a "real writer." Thanks to my amazing friends who kept inquiring about my thesis until it was finished, and for dragging me out of my writer's block and forcing sleepovers when I needed them the most. Thanks to my Dad for supporting me while in graduate school, especially to the large sum of money he's paid to Starbucks during the long hours that spent researching, reading, and writing there. Finally, thanks to my Mom who is no longer here, but who I constantly feel is right beside me pushing me along; you inspire me every day to continue to push myself in my education and to do the things that I think cannot do. You are my biggest inspiration. Also, thank you to my therapist, Sherri Ettinger, who has supported me throughout my time at Smith College and helped me to manage through many, many moments of panic and self-doubt, and who I maybe instilled some panic into, too, sometimes... I don't know how I would be here without all of your support.

I would also like to thank my amazing advisor, Rory Crath, who guided me throughout this process, encouraged my critical thinking, and continued to believe in my writing and learning process when I felt stuck. I feel very lucky to have worked with you on this project and couldn't have asked for a more attuned and kind advisor. Finally, thank you to Christian Rangel for agreeing to be my second reader.

TABLE OF CONTENTS

ACKNOWLEDGMENTS	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES	iv
LIST OF FIGURES	v
CHAPTER	
I. INTRODUCTION.....	1
II. LITERATURE REVIEW.....	5
III. METHODOLOGY.....	18
IV. FINDINGS	23
V. DISCUSSION AND CONCLUSIONS.....	34
REFERENCES	39

CHAPTER I

Introduction

The purpose of this study is to answer the following questions: How do gay and bisexual men identify and negotiate their experiences gaining access to Pre-Exposure Prophylaxis (PrEP)? What is the role of lay expertise in defining and shaping the Facebook group's discourse on *access*? My thesis seeks to understand how access is being negotiated between the health care system, resources and institutions by locating conversations about access to PrEP within the lay led Facebook group *PrEP Facts: Rethinking HIV Prevention and Sex*. [Office1]

For the purposes of this study, I have defined *access* according to my reading of articles related to *access to health care and equity* and divided the term into five categories of analysis: approachability, acceptability, availability and accommodation, appropriateness, and affordability. The focus of this qualitative study centers around the lives of gay and bisexual identifying men (gbm) and the ways in which the health care system moderates who gains access to the promising pharmaceutical interventions that are marketed to this population of health care consumers. Health care insurance plans, providers, resources, and the institutions of care that facilitate and hinder access [Office2] to preventative sexual health care--particularly health care in the form of Pre-Exposure Prophylaxis (PrEP) called Truvada—which is not only advertised to gbm but recommended for those with certain HIV “risk profiles” (CDC 2014). Gay and bisexual men are left to navigate an interlocking web of health care resources that can be observed on online social networking sites, such as the PrEP Facebook group which is replete with consumer-oriented information and where

members share personal experiences and knowledge about how they can best manage the gaps within the health care system itself.

One reason for conducting this study is because the results have the potential to inform the work of health care providers engaged in public health disciplines across professions--from social workers to medical providers. Since the number of gay identifying men who are turning to social media for public health education and advice is rapidly increasing, one can assume an increasing need for social workers and public health practitioners of myriad disciplines to understand the ways in which social networking sites are influencing the decisions of the “at risk” communities they serve. Little research has been conducted to understand the ways in which online health education is disseminated and constructed and how these narratives influence users’ online and offline lives. While discussions about health problems and concerns are increasingly moving online, pharmaceutical interventions are becoming more frequently utilized to manage individual health prevention and health problems. “Following recent trends in queers of color critique, we understand that these medications and the attendant discourses encouraging their use, have social lives all their own, including consequences for the communities they’re directed towards that reverberate far beyond the decision to take or not take a specific medication” (Crath, project description, 2016).

CHAPTER II

Literature Review

According to the CDC website, “Pre-exposure prophylaxis, or PrEP, is a way for people who do not have HIV but who are at substantial risk of getting it to prevent HIV infection by taking a pill every day. The pill (brand name Truvada) contains two medicines (tenofovir and emtricitabine) that are used in combination with other medicines to treat HIV. When someone is exposed to HIV through sex or injection drug use, these medicines can work to keep the virus from establishing a permanent infection” (Pre-Exposure Prophylaxis (PrEP), 2016). PrEP^[Office3] is primarily marketed to men who have sex with men or MSM of color, however the primary users of the drug are overwhelmingly white gay men. There are many reasons for this finding, which cannot fully be explored in this thesis. One way in which this phenomenon is captured is within the Facebook group---PrEP Facts: Rethinking HIV Prevention and Sex, where the most frequent users are predominantly white and class privileged. This thesis seeks to understand the ways in which whiteness is being privileged in the Facebook group due to the fact that the primary users of this medication are upper middle class white MSM or men who have sex with men. The group moderators promote the group within the realm of a health education framework^[Office4] focused on “fact-based information, understanding, respect, and compassion.” However, this advertisement in itself is misleading because fact-based information is not formally defined and seems to encompass personal experience, biomedical technologies, and political structures, which influence accessibility to a drug.

History of Human Immunodeficiency Virus (HIV)

When antiretroviral therapy was introduced in the United States in the mid-1990's AIDS (Acquired Immune Deficiency Syndrome) deaths in the United States dropped from roughly 50,000 per year to 13,000 according to the CDC (The Center for Disease Control and Prevention 1-4). Human Immunodeficiency Virus, or HIV, incidence (newly infected HIV persons each year) has remained relatively stagnant since the mid-1990's (*HIV Surveillance Report* 2015;26). In 2012, the CDC approved a medication called Truvada as a form of PrEP or Pre-Exposure Prophylaxis. Truvada was created by the pharmaceutical company Gilead and was found to significantly reduce the chance of HIV transmission. Truvada has been shown in clinical testing to be 98% effective in reducing, if not having the potential to eliminate the risk of HIV transmission among men who have sex with men (MSM).

Despite the advances in this type of HIV treatment commonly known as TasP or Treatment as Prevention, Truvada may not be as widely embraced for many reasons such as limited outreach and public education and limitations posed by insurance providers and even the medical community from embracing upon this new treatment. The cost of the medication is about \$13,000 per month, [Office5] which presents an additional barrier to HIV prevention in men who have sex with men or MSM. Difficulties in paying for medication and accessing PrEP-informed providers disproportionately affect the gay community. Gay and bisexual men in the United States account for 87% HIV incidence, or the number of persons newly infected with HIV each year.

Among MSM, HIV transmission has remained the same over the past ten years. According to the CDC website (cdc.gov), 50,000 new members of the gay community

test positive for HIV each year. Standard recommendations in HIV transmission have included the use of condoms as a form of prevention. In 2006, the CDC approved a medication in the form of PrEP (Pre-Exposure Prophylaxis) labeled Truvada. The drug company which makes Truvada—Gilead—funded a study called iPrex, which tested the drug's efficacy in preventing HIV transmission among MSM (men who have sex with men). The iPrex study proved that when taken daily, the drug is 99% effective in preventing HIV transmission. While the drug has been widely advertised to the gay community as a form of PrEP by Gilead, studies show that a significant number of people who take the medication are in fact MSM; 50% are women (women are not deemed an at risk group by the CDC). Reasons for lack of use among MSM may be attributed to multiple issues, including lack of provider knowledge about the medication, possible stigmatism—that MSM should use condoms and are not using condoms and are thus promiscuous and/or careless, the cost of the medication (priced at nearly \$15,000 per month) and the fact that most people living in the U.S. cannot afford this price, and lack of knowledge about the medication and side effects within the health care system and the institutions that comprise it.. Why are people who are being diagnosed with a disease continuously denied medication that could prevent chronic illness and lifelong antiretroviral treatment? Given our understanding that condoms are not foolproof and HIV positive cases continue to remain at about 50,000 new cases each year, why is this method of prevention still the one and only recommendation provided to MSM?

The Facebook group entitled *PrEP Facts: Rethinking HIV Prevention and Sex*, designed to promote discussion, inquiry, and express concern around PrEP and uptake of the medication includes the membership of around 17,000 Facebook users who are using

the group to discuss ways in which they may use the drug as a form of PrEP despite some of the barriers posed above, and discussed in the Facebook group. The group is the largest social media action dialoguing concerns, questions, and information about Truvada. While the group raises the question of what is being done to gain access to life giving medication—that almost promises health, a different way of life, sex without fear of disease, PrEP Facts is uniquely different from protests that have historically occurred in the HIV/AIDS movement of the 1980's given the shift from in-person community organizing to social media forums as ways of relating and forming community around a common issue. PrEP Facts, for instance, demonstrates wide discussion regarding the difficulty of gaining access to both the medication and the follow up care recommended by Gilead to maintain one's health while taking the medication. The group's moderators who advertise their presence as guardians of information about Truvada and managing the health care system, simultaneously are monitoring the group, and it remains curious how group members can discuss freely while simultaneously being monitored by both moderators and those who choose to join the group.

Lay Knowledge and Medical Knowledge [Office6]

In recent years, scholars have begun to focus attention toward deconstructing concepts of access to institutional power in the form of medical knowledge. I want to continue in this research by studying the concept of access to medicine and healthcare, and the systematic ways in which human beings are afforded and denied access (to health care) depending on the social identities one holds and corresponding markers of privilege. The system of marking human beings as deserving of access, goods, and

services is a product of colonization and is rooted in a long history of racism in the United States. Despite significant progress made during the civil rights, feminist, and gay rights movements, the process of colonization continues to persist in increasingly camouflaged forms in this current social climate. [Office7]

Laws governing access to preventative health (care) have regulated the behaviors and bodies of marginalized people throughout U.S. history[Office8]. Over the past several years, activists have begun to form and organize groups around health-related concerns that Epstein (1995) regards as particularly distinctive due to a pattern of group identity construction around a particular disease and focused political claims based on a shared identity status. Although these groups have not publicly acknowledged organizing strategies garnered through AIDS activism of the 70's, Wachter (1992) believes these new health-related activist groups are using strategies and vocabulary reminiscent of ACT UP. Common among these activism groups is a shared set of values or interests, including: a suspicion of biomedicine and its purported treatments, a repudiation of the "victim" status of being a patient within a complex and difficult to understand medical system, a desire for increased mutuality in the doctor-patient relationship and patient involvement in determining research priorities, findings, and making policy decisions based on research findings (Epstein, 1995). Unique to the formation of health related activist groups is a decision to value systemic healing over individual healing in a culture that increasingly influences masculinist ideals of independence, self-reliance, and strength over vulnerability.

Activist groups organized around social location provide a basis of "situated knowledges" (Haraway, 1991) or "partial, locatable, critical knowledges" that people

with HIV or AIDS have argued as credibility for inclusion in clinical trials providing experimental drug treatments. Activists able to navigate biomedical language and epistemological, methodological, political, and ethical claims were able to construct powerful arguments that proved effective in both specialized and public arenas; these efforts later provided convincing evidence for including AIDS activists into research funded by the Clinton administration (Epstein 1995).

Individuals are increasingly seeking to understand illness through searching and learning information about their own risk of illness, diagnoses, and course of treatment. This provides the individual patient with an ability to speak in medical terms without needing to ask what something might mean, which draws attention to the imbalanced power dynamic between patient and doctor. This ability to communicate easily with one's doctor facilitates a patient's sense of competence while in an already vulnerable position—medically compromised due to disease or even at risk of becoming ill.

Pitts' writing on illness and empowerment in the case of women writing about their experiences with breast cancer suggests the increasing association between online social support and survival, or improvement of symptoms. Pitts's writes, "Many of these narratives suggest, implicitly or explicitly, that becoming fluent in medical language and treatments is a key to actually surviving breast cancer, rather than a tool for decision making, psychological comfort or intellectual understanding" (45).

In *Social Support Strategies*, Benjamin Gottlieb discusses two types of preventive approaches to improve coping and health; these include strategies with a "primary preventive objective" and that which occurs at a "secondary preventive level." (1983;67). The second type of preventive strategy is described as a "mass-oriented, health promotion

strategy” aimed at those who are not assumed to be at risk of poor health. Such a preventive strategy entails restructuring existing social networks in order to optimize their “helping capabilities so that they may reach more people and more adequately fulfill people’s requirement for support” (1983; 67). Gottlieb specifies that broader support networks are aimed at those who are not in some way impaired by an inability to cope, and are not intended to coincide with a stressful event or stressor. “Only the most general social risk factors govern decisions about where and whom to extend these support development activities, namely, in settings where people tend to be socially isolated or marginal, and among populations whose social networks are resource deficient or structurally too weak to provide access to support. (Gottlieb,1983; 83). Various empirical studies have supported reasons for embedding people “in primary support networks that optimize their access to and use of informal supportive resources” (1983; 84).

In *Sociology and Health Promotion*, the authors argue that the facilitation of health promotion includes dissemination of health information, in addition to altering people’s social, economic, and ecological environments (Bunton et al, 1995). If health information is available, socio-economic structures “must encourage the creation and implementation of ‘healthy public policies’” (1995, 2). While much effort has been made to promote, contribute to, and refine health promotion strategies, there is a gap in attention and analyses of the practice of health promotion itself.

Health education has become increasingly present on the web in the form of social media websistes such as Facebook. Insofar as technologies are always already inextricably bound up with systems of power/ knowledge, they do not stand outside the

subject, but rather, are constitutive of the very categories ‘such as the real, the natural, and the body, which remain the bedrock of humanist forms of feminism’ (Munster, 1999: 122). According to Norman Fairclough, all forms of mass communication give rise to questions about access (1995). Fairclough argues that, in any mediated *quasi-interaction*, the consideration of whom is allowed to write, speak, and be seen, and who does not, is of great significance, as media is an institution highly influenced by institutional power and control. “Media output is very much under professional and institutional control, and in general, it is those who already have other forms of economic, political, or cultural power that have the best access to the media” (Fairclough, 1995: 40).

Access to Health Care

According to Rangel (The Beginnings of Canadian Health Care), access to health care consists of two parts: access to a *biomedical system*, and access to the systemic structures that strengthen or weaken health care and outcomes. Rangel argues that access can be measured by heeding to the “responsiveness” of the health care system in two contexts: 1) when individuals are actually receiving the services and goods as individuals in need of care, and 2) what is available to the individual’s peers. He argues that the biomedical system’s responsiveness and the structures that constitute that system are related to the concept of equity in health care but hold separate meaning from the concept of access. Equity is structural and informed by policy aimed at provisioning the services and goods available within the *biomedical system* evenly across myriad communities in need (Rangel, Beginnings of Care).

Levesque et al. (2013) acknowledge the complicated and complex meaning of the term *access* as it is applied to understand health care models around the world, and seek to navigate the breadth of literature regarding the meaning of this term. The authors synthesize the literature on the conceptualization of access and generate a new conceptual framework of access as it applies to health care systems and populations (Levesque et al, 2013). The resulting conceptualization is both comprehensive and changing according to relevant determinants “that can have an impact on access from a multilevel perspective where factors related to health systems, institutions, organizations and providers are considered with factors at the individual, household, community, and population levels” (Levesque et al, 2013). Access is defined differentially depending on the context to which the term is applied which suggests the dynamic nature of the term and the necessity to redefine the concept of access within each new context to which it is applied.

According to Webster dictionary, access is articulated through multiple meanings including, “a means of approaching or entering a place,” “the right or opportunity to use or benefit from something,” “the right or opportunity to approach or see someone,” “the action or process of obtaining or retrieving information stored in a computer’s memory, in addition to other meanings particular to multifarious other contexts. Levesque et al.’s comprehensive definition of the term as it applies to health care is defined as the following:

Within health care, access is always defined as access to a service, a provider or an institution, thus defined as the opportunity or ease with which consumers or communities are able to use the appropriate services in proportion to their needs (Patient centered access to health care, 2013).

Like Rangel (2013), the authors acknowledged the importance of differentiating between the actual use of health care and the need for health care, and between factors of supply—location, availability, cost, and appropriateness of services, and demand—illness, health knowledge, attitudes, health practices and self-care (Levesque et al, 2013). Given the changing and complex nature of the health care system in the United States, it is critical that health care providers understand how patients navigate and understand access to the health care services they need.

The U.S. biomedical system insists patients take responsibility for acquiring knowledge about individual health needs, problems, and resources and the ways in which they can afford to get health needs met within a market driven model of health care. Levesque et al. (2013) deem *patient centered perspectives* essential to population and system level approaches, combined with demand and supply factors in order to produce an operational definition of access that includes obtaining and benefitting from health services. Levesque et al (2013) summarize the most frequently cited frameworks for access which are utilized to conceptualize *five dimensions of accessibility of services*: 1) Approachability; 2) Acceptability; 3) Availability and Accommodation; 4) Affordability; 5) Appropriateness. These dimensions are described in relation to *five corresponding abilities of persons* to generate access, which include: 1) Ability to perceive; 2) Ability to seek; 3) Ability to reach; 4) Ability to pay; 5) and Ability to engage (Levesque et al., 2013). For the purpose of this qualitative analysis, the five dimensions of accessibility to services were defined and broken down into smaller

categories or themes, which informed coding of the Facebook page for discussions related to accessing PrEP as Truvada.

CHAPTER III

Methodology

The purpose of this study is to research the ways in which Facebook group members navigate access to the most effective preventative HIV medication, known as PrEP, which when taken as prescribed, has been found to be 99% effective in preventing HIV transmission. The Center for Disease Control approved the drug—Truvada—as a form of PrEP in 2012, and for MSM who have been able to obtain the drug and take the medication as prescribed, the medication has afforded MSM to change the ways in which they approach their bodies, sexual health, and relationships, as PrEP uptake diminishes fears of contracting HIV and allows MSM to engage in sexual relationships without fear of consequentially needing to take anti-retroviral medication for the rest of their lives, as a result of a less effective preventative options. My thesis seeks to understand how access is being negotiated between the health care system, resources and institutions by locating conversations about access to PrEP within the [lay led](#) Facebook group *PrEP Facts:*

Rethinking HIV Prevention and Sex.

Sample

Purposive sampling, a nonprobability sampling method was used to explore the field placement experiences of MSW students. Purposive sampling is innately biased since the goal is to collect data from a very specific group. However, the need to locate such a sample offers justification for the sampling method. This type of sampling does not allow for generalization; therefore, the results of this research study will only aim to represent the voices of a limited number of MSW students.

This qualitative research study was open to MSM who are members of the Facebook *PrEP Facts* page and used the narratives constructed within the Facebook group to analyze access to PrEP. Since Facebook is a public social networking website, and anyone can join the Facebook group, the research study did not require an effort to seek informed consent of the Facebook group participants. By contributing to the Facebook page and engaging in discussions/ threads, members are aware that this information is privy to the public observer, as there are no formal requirements to join the group. When identifying information was labeled within the Facebook discussions, this information was excluded from the content analysis and considered irrelevant, due to a commitment to maintain confidentiality of group participants and because identifying information was not relevant to this qualitative study and understanding notions of access to health care among MSM. While not all participants identified as MSM, and women were allowed to join, participate, and engage fully in the group, this study remained focused on experiences of MSM seeking PrEP, as previous research has pointed to the differential experiences of MSM and other subjugated populations of seeking preventative sexual health care.

Ethics and Safeguards

In accordance with federal regulations and the ethics of the social work profession, the identities of study participants have been kept confidential and no identifying information was revealed or used in the data analysis. Special attention was paid to conceal any identifying content. Participants of the Facebook group contributed to a public forum, which is public information, given that all that is required to join

Facebook and this Facebook group is an email address and one must request to join the group.

Data Collection

In order to explore discussions of access to PrEP in the Facebook page, qualitative data was obtained through coding Facebook discussions or threads for five analytic categories that denoted patient centered access to health care. These five analytic categories were chosen based on the extensive literature review performed by Levesque et al (2013) in the article, “Patient centered access to health care: conceptualizing access at the interface of health systems and populations.” Using the conceptualization of access articulated in this article, I discerned five main analytic categories for which data was collected: Approachability, Acceptability, Availability and Accommodation, Affordability, and Appropriateness.

A round of data collection of five analytic categories in the PrEP Facebook group [was conducted](#). By data collection, I mean, collect threads and individual posts that include phrases and sentences associated with dimensions of each analytic category. (These dimensions are listed below, under each analytic category.) This constituted a first round of searching through the data on the PrEP Facebook page. Through my reading of articles related to *access to health care* and *health equity*, I have compiled a list of analytic categories for data collection. Each analytic category was broken down into concepts or dimensions that give meaning to the overarching analytic category. The analytic category that is not included in this data collection is *online health forums/ support groups*. I used the

data from this first round of data collection to assess how and in what ways users are using the support group to define and mobilize around issues of access. ~~I asked the research assistant~~ This preliminary coding was used to systematically search for corresponding dimensions of the analytic categories in the PrEP Facebook group.

Approachability

Approachability includes general themes of knowledge seeking, information, need(s), identification or acknowledgement of HIV viral load, AIDS diagnosis, or a need for a more effective prevention tool than condoms, perception of one's own HIV risk, and acknowledged sexual practices/behavior. The context for the search is that *approachability* references an individual's understanding that, a certain type of health care exists, and that this care holds the possibility of impacting the health of the individual (Levesque et al, 2013, 12).

Acceptability

Acceptability includes general themes of: how experiences of sexual identity, race, gender, ethnicity, identity and identified friendship networks influence decision to take PrEP; values and beliefs about pharmaceuticals, sexual practices; autonomous decision making, personal choice, preference; rights, equity, justice, and intention. The context for the search is that *acceptability* references the social norms, factors, values, and belief systems that determine whether the individual is fit to receive a certain type of health care (Levesque et al, 2013, 5).

Availability

Availability pertains to general themes of: qualification(s), qualified professional/provider, closeness and distance, issues of transportation, amount of time or time spent at the health facility or accessing facility, flexibility and inflexibility, scheduling, attentiveness, able/ability, obligations/responsibilities, distribution of resources. The context for the search is that *availability and accommodation* reference the tangible health services that have the capacity to provide services in a timely manner (Levesque et al, 2013, 6).

Appropriateness

The themes: effectiveness, helpfulness, satisfaction, positive/negative experience, communication, explanation, feeling heard/seen/listened to, empowerment, hopefulness/helplessness, motivation, discrimination. The context for the search is that *appropriateness* references the relationship between the quality of the services provided and the scope of the patient's health care needs (Levesque et al, 2013, 6).

Affordability

The general themes include: expense, cost, employer/days off/work, health insurance, out-of-pocket costs, income, borrowing, price, debt, poverty, social isolation, financial assistance/opportunity, coverage, financial stress, Gilead or state sponsored programmes for PrEP. The context for the search is that *affordability* references one's ability to spend personal resources and time on services that fit the individual's specific health care needs (Levesque et al, 2013, 6).

Data Analysis

Analytic Category: Availability and Accommodation

In analyzing the data collected tagged "Availability and Accommodation," I

noticed several themes which challenged medical authority and dominant white middle-upper class gay male perspectives^[Office11] on PrEP uptake and use. In one thread, a group member raised concerns about running out of his PrEP prescription several days prior to receiving a new script, and asked if anyone in the group could spare three days of PrEP in order to cover the gap between when he runs out, gets a new prescription and is able to refill the medication. Two group members quickly reply that they can provide the needed medication and offer understanding as they too, have run out and needed to borrow PrEP before.

This vignette illustrates the systemic fault line in a health care system that presents a conflict of interest with PrEP users normal lives, and insists one must be a “perfect patient” in order to receive the health benefits afforded by the health care system, which in this case involves access to a medication that prevents HIV transmission and essentially, prevents one from becoming a chronic patient^[Office12]. This particular example notes the health care system’s lack of accommodation for PrEP users normal lives by placing the responsibility on the individual person to accommodate themselves to a rigid health care system with inflexible rules. For instance, in order to be prescribed PrEP and take it daily as prescribed, an individual needs to see a medical provider every three months in order to obtain prescriptions for the next three months. This brings up concerns about whether an individual has a health care provider who makes the drug available to their MSM patients, has appointments available for patients within a reasonable time period so that the patient can see them before running out of medication. The original poster of the thread mentioned above noted, “I am generally bad at filling prescriptions on time—Damon knows!—because of my work and school schedule, so if I

ever need help again, I will reach out ☺.” This example points to the lack of accommodation for MSM to live normal lives, forget to refill a medication or not have the time to schedule and go to a doctors appointment, as this is a frequent occurrence for busy working students. However the medical system withholds PrEP from PrEP users if they do not accommodate their time, money, and energy to obtaining the medication. Despite the punitive nature of this system, the original poster was supported by several people on the Facebook page who offered to help and supply PrEP until the poster could refill his prescription. PrEP users in the Facebook group have managed this gap in health care services by lending and borrowing pills as needed. PrEP users make the medication available to one another when facing multiple barriers to acquiring medication on time.

In thread 2, a group member raised concerns about changing health insurance due to moving jobs and asks the group about whether her new insurer will accept the co-pay voucher at her local pharmacy. She asks the group how to manage the change in health insurers and concerns that PrEP will not be covered with the Gilead copay card. The new insurance company limits the poster to use particular pharmacies (if one needs to use the voucher to afford PrEP, since such “specialty medications” are not covered by all health insurance companies). This thread highlights the complicated web of navigating what it means to be “covered” by one’s health insurance in order to receive the health care and medication one needs. Group members voice personal experience where the pharmacist was unaware of a Gilead voucher and inquired if they “knew the cost” of PrEP and advised the original poster to be persistent by instructing the pharmacist in recognizing and using the copayment voucher. Another group member notes, “Did not have to pre-authorize. But the CVS copay was astronomical, something like \$200 for 30 day supply.”

This example illustrates that one must either have plenty of time in order to inform pharmacists about copayment vouchers for PrEP and facilitate voucher carry-over from one insurer to another. The health care system appears to communicate that one must have additional time and/or money available in order to afford PrEP, as the consequence of not educating a pharmacist or calling one's insurance company to ensure recognition of a Gilead voucher is an "astronomical copay" which can only be afforded by the wealthy on a monthly basis.

The request for a PrEP prescribing provider occurs on multiple threads throughout the Facebook page, as MSM seeking PrEP raise concerns about providers not knowing about PrEP and not recommending PrEP when during discussions about sexual health in their doctor's office. In thread 3, a group member asks, "Is there a registry for PrEP friendly Dr. I need a new Dr." One of the group's moderators responds with a link to a new registry of PrEP friendly providers in the U.S. (launched on September 14, 2016). This highlights the lack of education amongst health care providers, if they are choosing not to recommend PrEP or do not know of the medication Truvada. On a later thread a poster notes, "I asked my doctor to order PrEP for me, he said that he'd heard about it but had never written a script for, didn't know what to write!!?" When medical providers are not knowledgeable about HIV prevention, PrEP is rendered unavailable from providers and MSM are not accommodated by the health care system which one might expect to inform them about how to best care for one's physical and mental well-being. For the provider who did not know what to write, a group moderator suggests the original poster provide their provider with a CDC hotline and website that will guide the provider to learn about PrEP and prescribe "ethically." Thus the responsibility is placed on the

individual to know, educate the health care provider, and/or offer information to the doctor to inform them about Truvada. MSM on the Facebook page have also managed this gap in the healthcare system by accruing a list of providers who PrEP users have experienced as willing to discuss and prescribe the medication. The moderators who suggest MSM inform their providers about how to best care for them assume the patient has a relationship with their provider, and possibly a very strong one, given that feedback about how to do one's job may not be received well in all circumstances. The medical model suggests that one must be responsible for making PrEP available as providers are, in many cases, not making the drug available to MSM.

Analytic Category: Affordability

To locate conversations about *affordability* of PrEP, I searched for general themes of cost, expense, employer/work/days off, health insurance, out-of-pocket costs, income, borrowing, price, debt, poverty, social isolation, financial assistance/ opportunity, coverage, financial stress, Gilead, or state-sponsored programmes for PrEP. The context for the search is that *affordability* references one's ability to spend personal resources and time on services that fit the individual's specific health care needs. Pill lending and borrowing was frequently discussed as a solution to affording Truvada.

Within discussion threads revolving around *affordability*, the topics of health insurance, co-payments, coverage, vouchers and programmes that assist some individuals to afford PrEP were noticeably common. In the following example, a poster brings the group's attention to the rigidity of the health care system, as some mail order pharmacies do not accept the Gilead co-pay assistance card (which many use to afford Truvada) and

instead require that one pay for the medication up front and then submit the receipt for reimbursement to their insurance company. To submit payment for one to three months of Truvada up front is costly, however this “solution” is only available to those who can afford to do so. A commenter mentions that a claim should be filed within a certain number of days in order to be reimbursed by the insurance company, depending on the insurance company’s precedent. Again, this highlights the patient needs to be informed of their insurance companies policies, able to afford PrEP up front with the financial security to wait for reimbursement, and must have the time to read, learn, and understand these rules for their particular plan, insurance coverage, and budget.

Conversations about *affordability* frequently discussed the Gilead co-pay card, which covers \$3,600 of Truvada expenses on a yearly basis, as the card can be exhausted before the end of the year depending on the amount one’s insurance policy will cover or whether one has health insurance to assist in paying for Truvada at all. In one thread, a poster states that a friend has exhausted their Gilead co-pay card for the year, and asks if group members know of other resources that he may direct his friend toward. Multiple group members relate in the following statements: “I’ve done the same. I haven’t figured out a solution yet. I’m somewhere between \$400-\$600 of my out of pocket maximum and I might just try to budget for that so I can 3 month refill on more time this year.” This poster notes they used the copay card to pay “my initial \$2k medical deductible—something I couldn’t do last year so I’m thankful for Gilead expanding the terms like they have!” Group members go on to discuss options such as government-paid PrEP under a public insurance program or county health department “if they cannot otherwise get it.” This example highlights the inflexibility of insurance services as many still do not

provide sufficient coverage for PrEP and hold the individual responsible for payment, despite large out-of-pocket costs, that frequently cannot even be covered by the \$3600 Gilead copay card. This suggests that the health care system will only afford to provide medication for those who are capable of paying large health insurance deductibles and copayments not covered by the Gilead copay card. MSM in the Facebook group are managing the health care system's failure to provide affordable PrEP medication through alternative avenues such as using a mail order pharmacy from India that provides the generic form of Truvada for \$55.00 per month, which is far more affordable than the price of Truvada in the U.S. health care system. One group member notes, "It is heartbreaking to hear of people unable to get this when they need it. I'm so fortunate that my insurance covers all tests and just leaves a \$30 per bottle copay which Gilead absorbs. I'm guessing that if the time ever comes that I do not choose PrEP I will find someone who needs it and keep filling that RX." This quote reiterates that the health care system requires an individual have adequate access to financial resources in order to obtain a needed medication and otherwise leaves poor and working class MSM without needed healthcare, despite if they pay into the health insurance system or not.

Another thread representing affordability attends to the difficulty affording PrEP even with insurance and assistance. For example, a thread begins with a poster informing the group he has been on PrEP for nearly a year, and has learned that his insurance company requires "labs are up to date and meet the certification requirements for approval." The poster notes that he and his partner have staggered their refill dates in case they run into a delay with the insurance company in the future and anticipates further barriers to affording PrEP: "Our plan is going up in January from about \$1600 to about

\$2100 per month so we are watching these types of articles very carefully. After Nov. 1, we will get serious about considering options for 2017.” The poster illustrates that, in order to receive proper health care, he needs to consistently pay attention to trends in his insurance company and where else they can look for financial assistance in order to afford needed medication. A group member summarizes the medical model’s imposed financial barriers to affording PrEP rather accurately: “I think there isn’t so much a problem with denials as there is with deductibles and co-pays. They will cover you for PrEP...but the PrEP consumer’s share of the cost may make it difficult if it exceeds the Gilead co-pay assistance limit. This doesn’t even take into account labs and co-pays for office visits.” This thread points to the inaffordability of PrEP in the current medical model, despite insurance companies claims to “cover” a medication. Group members are managing health insurance companies’ lack of coverage by acknowledging the time, effort, and attention required in order to afford PrEP, and that such an approach is exhausting and not viable in the long term as costs are increasing and insurance companies are barely covering insured patients, since many insured can still not afford Truvada.

The facebook group infrequently discusses options for affording PrEP for uninsured MSM. In one example, a group member posted the abstract of a study that denoted “Condoms are preferred over oral PrEP two-to-one, according to this study of MSM in the United States”; the study is entitled, “Preferences for Long-Acting Pre-exposure Prophylaxis (PrEP), Daily Oral PrEP, or Condoms for HIV Prevention Among U.S. Men Who Have Sex with Men.” Multiple members problematize the study and argue that what one may claim in a study does not necessarily correlate with behavior,

and that in one group member's experience, upon suggesting PrEP to younger partners, several of them have pursued PrEP instead of condoms. A group member notes, "For those without insurance, condoms may be the only economically viable option....It would be interesting to drill down to see if the percentages in this age group (re: young MSM) changes significantly where government programs cover PrEP." This vignette illustrates the inaffordability of PrEP for young men who are less likely to have health insurance than those who are older and possibly more established in their careers or jobs. Group members bring attention to the problem that young MSM and poor and working class MSM do not necessarily prefer condoms but are left with this option (as PrEP is rendered not an option given the high cost of the medication if one does not have health insurance or government assistance in paying for PrEP. The medical model in the United States is reiterated as inefficient as it provides insufficient support of those who are covered by health insurance and paying sufficient amounts of money into the system; for those who cannot afford to pay for health insurance or cover high deductibles, PrEP is entirely unaffordable and not a prevention option. The alternative is far less effective and is associated with far higher risk of HIV transmission, but the health care system appears indifferent to caring for individuals who are not wealthy and contributing thousands of dollars to the health care industry on a yearly basis.

Analytic Category: Acceptability

To locate conversations regarding "Acceptability" of PrEP, I searched for general themes of how experiences of sexual identity, gender, race, ethnicity, identity and identified friendship networks influence one's decision to take PrEP; values and beliefs

about pharmaceuticals, sexual practices; autonomous decision making, personal choice preference; rights, equity, justice, and intention. The context for the search is based in an understanding that *acceptability* references the social norms, factors, values, and belief systems that determine whether an individual is fit to receive a certain type of healthcare. This analytic category was the third most frequently occurring topic after *Affordability* and *Availability and Accommodation*.

Within discussion threads about *acceptability*, discussion about how race, sexual identity, gender, and identified friendship networks influencing one's decision to take PrEP occurred most often. In one example, a young man of color (MoC) begins a new conversation:

“I am realizing from asking my friends who aren't on PrEP that people do not realize that you have to go to the doctor every three months to be on PrEP. They think you just get it and are left to the wolves. Like once I explained I will be going to the doctor 4 times in a 12 month period to have my health screened that was actually something they reported changed how they felt about it that became more supportive.”

In this thread, a PrEP navigator inserts himself stating that PrEP is a “gateway drug” to being more informed about one's health, and reiterates what the initial commenter stated about getting more health care as a result of PrEP. The commenter highlights the lack of information provided to his friends, who he later states “are all young MoC.” This thread highlights the healthcare system's lack of reach to communities of color, and the perception and possibly lived experience that young MoC will be left to navigate a highly complex health care system

without much guidance or support from a medical provider. The original poster has highlighted the ways in which he is facilitating this gap in the health care system—a health care system, which one might argue is very dependent on the financial resources and support network of individuals also taking PrEP—through educating his informal network of friends about how he has managed to get PrEP and remain on PrEP despite perceived obstacles which were not expanded upon in this vignette.

CHAPTER IV

Findings

This chapter outlines the findings from the data collected during the one and a half months of thematic coding the *PrEP Facts* Facebook page for themes delineating access to health care, specifically access to the Pre-Exposure Prophylactic medication Truvada. Three major themes emerged in the analysis of the selected qualitative data delineating categories of access. First, conflicts of interest rooted in affordability were reported as the most significant factors limiting access interventions within the health care system. Second, elements of availability and accommodation to PrEP within the health care system were identified as influencing the ability of MSM to fully gain access to sexual health care and become consumers of PrEP. The findings are organized in three major sections: affordability, availability and accommodation, and acceptability. This last section is divided into three subcategories: conflicts of interest, organizational attitudes, and perceived impact on quality of life as it pertains to relationship with self and others.

Access to Preventive Health Care: Availability and Accommodation

Within discussion threads coded for *availability and accommodation*, the following themes emerged from the data: (1) running out of PrEP; (2) lending/ borrowing pills until a group member is able to refill their prescription; (3) discussion of health insurance companies and plans, and specifically who will accept the Gilead co-payment voucher; (4) educated and informed providers; (5) discussions around responsibility of

the individual to navigate healthcare resources and institutions versus the fairness of U.S. medical system and access to healthcare; (6) difficulty obtaining medical records or transferring medical information from one system of care to another (e.g. from a clinic where blood tests were done to the doctor's office, for instance).

Group members discussed the difficulty in managing different systems of care and facilitating communication between different providers. One poster disclosed his experience in trying to get his community clinic (where he received his quarterly HIV screening) to his primary care doctor and experienced multiple barriers to accessing PrEP. This poster is a retired doctor himself had completed the screening and attended his doctor's appointments on schedule (or ahead of the time PrEP needed to be refilled):

“I just spoke to (doctor at community clinic). She doesn't know why my requests to send records to the doctor have not been honored, but is asking them to do this today. Apparently they reviewed this with the privacy officer when I made my original request. They were supposed to fax records to the doctor's office, but they won't fax records to individuals. She's not exactly sure of the privacy officer's rationale for this, but that's the rule. They'll mail you your records, but there's a separate form for this, which apparently has been hidden in obscurity somewhere. It has been so hidden, that no one seemed to know that it existed. You can't just use a medical records release to get your own records because—why? ... The more I think about this, I still don't understand why it's OK to fax records to the doctor, but not the patient upon their own request and consent...I agreed to receive my results by mail, because for now it seems

it's the only option I have. The problem I foresee is that we're realistically talking a week between requesting the results and having them show up in the mail. Then if they don't, you have to reiterate the request, and weeks go by before you know that no one is responding to your request.... When there are so many steps and pauses in the system, it still seems I'm likely to not know there's a problem before it's too late to fix it without medication interruption."

Limits to accessing PrEP contextualized conversations about consequences of geographical locations where PrEP is less frequently made available by the health care system, as evidenced the following example.

"I am right now at the HIVR4P in Chicago, and had the same thought about how many get HIV just because PrEP is not available for everyone everywhere." (HIVR4P is the world's first and only international scientific meeting dedicated to biomedical HIV prevention research, according to hivr4p.org.)

As noted above, lending and borrowing pills was a frequent discussion topic that was welcomed and responded to within the Facebook group. One poster commented, "What does one do with unopened unused bottles of prep?" to which a member posted, "Mail them to me!" Within the same thread, the legality of selling medication was raised, however another poster inquired about whether this was true for giving medication away, too.

Threads about running out of medication involved posters asking for help around how to manage this fault in the healthcare system that places the onus of responsibility on

the patient to be up to date with their labs (every three months), doctors' appointments, and to free up the time and space to either order the medication online (through an online pharmacy) or travel to a pharmacy that will accept the individual's health insurance and Gilead co-pay card. A group member commented on this issue in the following example, where he responded to a number of threads about how some who are prescribed PrEP "decide" not to take the medication despite having "immediate access to the best healthcare":

"I don't think that you can interpret this information as a lack of responsibility to HIV persons, as much as the lack of responsibility to the US system of unfair access to healthcare. Obamacare is trying to alleviate this serious problem, but if someone like a Trump gets into office, any reforms will be delayed as it was in the Reagan era. Today, in the U.S., 50,000 people are infected. And lots of them don't get tested and don't receive medication."

Access to Preventive Health Care: Affordability

Within discussion threads about *affordability* of PrEP, multiple themes emerged. These themes included discussions about: (1) insurance benefits; (2) whether or not one can receive benefits or PrEP without insurance; (3) concerns about continued insurance coverage following the presidential election, and potential consequences of losing Obamacare; (4) PrEP assistance programs by state and what is covered/ not covered; (5) health care deductibles and whether prescription costs go toward insurance deductible.

One poster raised the topic of insurance deductibles and whether pharmaceutical

costs specific to paying for PrEP are included in the deductible or are considered exempt:

“Yes, I am on an employer based health plan which is on a calendar that resets May 1. My coinsurance on Tier 3 for drugs is 50%. So assuming 50% coinsurance = \$600 per month for Truvada, I’ll be fine January-April but will use \$2400 of my copay insurance during that time. If I’m able to find a different plan starting May 1 that has lower (under \$200) copays for Truvada, I’m in good shape. If I end up needing to stay on my current plan, I’ll run out of copay assistance halfway through the year.”

In response to this poster, a group member confirms the deductible makes a significant difference in PrEP affordability:

“If you have a reasonable deductible that prescriptions and other medical expenses contribute toward, that \$3600 you spend that’s covered by the co-pay card counts toward meeting the deductible (in effect, in that situation, the co-pay card reduces your deductible by \$3600 if you use it up early in the plan year.”

Despite having insurance and investigating the ways in which the health care works with individual providers and plans, MSM still are left with the responsibility of finding alternative ways to budget money or attempt to pay for preventive health care and services.

Group members discussed the multiple ways in which the Gilead card can be used depending on each individual’s health insurance and plans, and ways in which they can both be cost effective for themselves while maintaining access to

PrEP and also mindful of other MSM who may not be able to afford PrEP. This is evidenced in the following discussion:

“Certainly using the Gilead card through my mail order is the best way. I’m essentially getting 3 months supply for the same cost as 1 at retail. Does the reim card go through McKesson? I haven’t looked at the card in depth yet as I’m unsure how the clinic will work with all of this. Regardless, I’ll at least be covered for 6 months of PrEP and then should be into my deductible at that time and can then cover it myself...” In response a participant advised the original poster double check their calculations, “depending on your max out-of-pocket limit and what other expenses you might have, using up the co-pay card without the clinic’s help might save you money. Depending on what the state is paying to help you, you may also be helping your fellow NYers and those in your insurance pool by taking advantage of Gilead’s discount.”

The original poster concludes that he would rather pay what he can, and acknowledges that others are not as privileged and still need access to PrEP, wherein the medical model has not been a facilitative factor to accessing PrEP. “If I can use my mail order in conjunction with the reim card from Gilead, that may certainly be the better route rather than using state funded money and leave that for someone else that truly cannot afford it.”

The topic of affordability in the U.S. was raised in discussion about comparative retail costs of Truvada internationally. One poster expressed surprise upon hearing a retail cost of about \$1,300 per month, as he was familiar with the

retail cost in South Africa, which he stated was about \$45 USD and that “the cost for all ARV’s in SA was slashed due to negotiations by Bill Clinton with the drug manufacturers. I can’t fathom why the same can’t be done for US citizens, especially since PEPFAR is spending billions of US taxpayer dollars in SA alone.”

In another thread, a member comments about having to endure the process of signing up for the Gilead assistance program a second time after changing his health insurance. The following example highlights not only the exhaustion of individual MSM’s fiscal resources but also the lack of clarity around what the cost of PrEP will be once the deductible has been met, which often comes as a surprise for MSM who can even afford to pay the deductible.

“Had been on the assistance program which took me over six months to get approved. My assistance expired and they wanted me to go through the steps again. I happened to change insurance companies with a \$2000 deductible. The first time I tried to fill my rx the cost was \$1000. The second time I tried to fill the script was in Aug. my deductible has been met and the cost was \$800. This is FU.”

This vignette demonstrates the experience of many MSM echoed throughout the Facebook group, where PrEP users get caught when changing health insurers, or changing any of the dynamic pieces of the health care system. When moving from one provider to another, using a different pharmacy, moving to a new area, or changing any aspect of one’s health care, a new gap in affordability appears, of

which the responsibility of bridging the lack of coverage is placed on the individual in need of the health care services.

Access to Preventive Health Care: Acceptability

Within discussion threads coded for *acceptability*, multiple themes emerged, however discussions pertaining to this analytic category typically involved navigating relationships with medical providers or locating accepting or doctors who others have experienced as “PrEP friendly,” meaning they have prescribed PrEP in the past and patients have reported an overall positive experience with the doctor. In this analytic category, the following topics or themes were discussed: (1) experience with primary care providers not accepting of PrEP; (2) providers making assumptions about MSM as careless or making decisions for patients about whom they may have sex with; (3) providers refusing to write scripts; (4) managing providers’ stereotypes about MSM and providing resources to educate their providers if not able to go to a new provider. The following is a statement about educating a primary care doctor about PrEP:

“At my yearly physical several weeks ago, my PCP and I had a conversation about PrEP. I’ve been taking it for 3+ years and was one of her first patients to start using Truvada as PrEP. She was reluctant to prescribe it but gave it to me anyway. She now advocates for it with patients at higher risk for HIV.”

Threads within this analytic category of access detailed how doctors or providers’ biases can impact MSM’s ability to access PrEP. One commenter posted a link to

a study revealing high levels of judgment among providers. In response to ethical concerns about medical practice, a group member creatively responded and suggested one way to bridge the gap between providers' discriminatory practices and MSM's access, as evidenced in the following example:

“And as long as doctors discriminate, it is perfectly ethical to lie to them and achieve the outcome which is most beneficial to YOU.”

Group members discussed the availability of state-funded programs for PrEP as an alternative option to afford the medication. “I’m getting involved in a state funded program in Central NY as I cannot afford it. My deductible is \$3000/yr... try checking out your local clinics or state hospitals and see if they have any programs available.” However for group members who cannot afford to pay \$3,000/year for a deductible, or who may need to switch insurance, employers, or who have no insurance at all, how will they be able to afford PrEP?

CHAPTER V

Discussion

The objective of this qualitative study is to explore how access to preventive sexual health care is being negotiated between the health care system, resources, and institutions by locating conversations about access to PrEP within the lay led Facebook group *PrEP Facts: Rethinking HIV Prevention and Sex*. The findings confirm that discourses on access within the Facebook page reflect the complex and dynamic process that the health care system requires MSM to undergo in order to receive needed preventive health care services. These findings are consistent with the literature presented in previous chapters highlighting the meaning of access to preventive sexual health care for MSM and the impact of lay led social networking sites in understanding access to PrEP. This chapter is organized as follows: 1) key findings, 2) strengths and limitations, 3) implications for social work education, and 4) recommendations for future research.

Key Findings

Data analysis led to two major findings. First, factors within the social climate of the U.S. medical model as an institution were found to disadvantage MSM's ability to understand and navigate the health care system, and gain access to PrEP. Second, organizational control rooted in the maintenance of business interests and relationships emerged as a factor limiting MSM in the Facebook group to gain access, and generated

discussion about how to manage these fault lines that create differential access to PrEP among MSM. The health care system, resources, and institutions were found to impact MSM's access to preventive health care. In the following subsections, I examine how these findings relate to previous research: 1) the use of social networking websites, such as Facebook, to highlight fault lines in the health care system and 2) the ways in which MSM are managing the gaps in the health care system to prevent HIV transmission.

Social Networking Sites Highlight Faults in Health Care System.

Users of the Facebook group *PrEP Facts: Rethinking HIV and Sex* demonstrated difficulty accessing preventive health care congruent with the CDC recommendations for MSM who are labeled a “high risk” group (CDC 2014). As stated in the 2014 PrEP Guidelines, “The only medication regimen approved by the Food and Drug Administration and recommended for all the populations specified in this guideline is daily TDF 300 mg co-formulated with FTC 200 mg (Truvada).” (CDC, 2014) MSM on the Facebook page shared experiences regarding access to PrEP—these included problems with affordability, availability and accommodation, and acceptability of PrEP. These findings point to the “enormous flaw in the dominant model of medical care: as long as medical services are sold as commodities, they will remain available to only those who can purchase them... the development of effective therapies may have a perverse effect if we are unable to use them where they are needed most” (Farmer et al., 2006). MSMs' narratives on the Facebook page further suggested that by viewing access to preventive sexual health care as structural issues related to cost, availability, and accommodation and availability of PrEP that hinder MSMs' adherence to preventive

sexual health care treatment as recommended by the CDC, it is possible to minimize the inequalities in access to PrEP.

Fault Lines in Health Care System Place Responsibility on MSM to Fill Access Gap.

MSM in the Facebook group consistently raised experiences, concerns, and problems related to accessing necessary and critical health care services in order to prevent HIV transmission. Group participants reported that their health care providers, doctors offices, pharmacists, health insurance companies, and related health care agencies and institutions focused on the strategies, skills, time, and money required to access PrEP rather than facilitating this process for the patient. On the other hand, MSM within the *PrEP Facts* group frequently provided answers, resources, and medication to one another with limited support of the health care system and its constituents. Group participants reported a wide variety of barriers to accessing Truvada as a form of PrEP at their providers' offices and clinics, and within the state funded systems purportedly created to ease access to sexual health care. As identified by Wilkenson & Pickett's (2010) study of health inequalities across developed and less developed, poorer countries, more egalitarian societies tend to be healthier and spending on high-tech health care is less important to a nation's health. This is consistent with the literature which highlights that countries that are more equal in terms of income tend to have healthier populations overall. Multiple MSM in the Facebook group were able to pay significant fees in order to receive access to PrEP, however as mentioned in earlier literature, MSM who are most in need of the medication in the United States lack access to the medication.

Strengths and Limitations

There are several strengths present in this study. First, the research contributes to a basic understanding of the relevance of social networking and lay led knowledge in order to determine one's health care decisions in order to prevent long term illness and/or disease. Moreover, this study contributes new findings to the fields of social work and health care, which may serve as a basis for subsequent research on the topic of MSM, access, and preventive health. Content analysis allowed for an unobtrusive approach to collecting data, which did not require contact with members of the Facebook group, and was useful in understanding patterns in understanding access to PrEP among MSM.

The study had several limitations including the use of a small sample size of one and a half months of collected data. The data also is limited to only MSM who have access to Facebook itself and/or know about the group. While the size of the Facebook group is rather large with nearly 18,000 members at the time of this writing, the group was not always welcoming to all MSM and it was noted that some MSM had left the group for myriad reasons. Therefore, the findings are only representative of the voices of the participants of the *PrEP Facts* Facebook group and cannot be assumed to be characteristic of the experiences of all MSM. In addition, given the frequency at which the topic of affordability of access to care was raised, one might consider who was left out of the Facebook discussions due to inability to afford insurance and the copious costs associated with gaining access to PrEP.

Implications for Social Work

This study's findings have direct implications for the field of social work and, more generally, the training of professionals in the health care field. The attitudes held by health care providers at micro, mezzo, and macro levels of the health care system were

found to remarkably influence MSM's access to PrEP as was demonstrated in the Facebook narratives. Experiences and contact points between MSM and the health care system were found to have longer term consequences in hindering or facilitating access to PrEP and in turn, taking care of one's health in ways that are effective and truly preventive. Contact with the health care system and experience of ease of access or gatekeeping access to necessary health care was a major factor influencing MSM's overall well being and sense that MSM can seek and actually receive effective sexual health prevention. The field of social work names commitments to service, social justice, integrity, competence, and values the dignity of worth of the person and the importance of human relationships (NASW, 2008). My hope is that these findings encourage social work and health care professionals to expand on this research and explore ways in which the health care system can facilitate access to health care instead of placing the burden of access on the individuals who are most in need of care and preventive services. The United States may be the only country in which such a wide array of advanced biotechnologies have been proven to prevent and cure chronic illness and disease, and where people frequently become chronic patients of the health care system because these advanced biotechnologies are available to such a small percentage of the overall population.

Recommendations for Future Research

The social work profession would benefit from further research that focuses on effective and widespread access to sexual health care for MSM, in addition to continuing to explore, investigate, and advocate for program policies and procedures that facilitate better health care of the clients we serve. It is critical that social work professionals focus

on all aspects of our clients' lives, rather than focus exclusively on mental health as if disconnected from the body and physical and sexual health. The field of social work prizes a commitment to social justice and professionals must attend to social inequalities in accessing psychological, physical, and spiritual care in order to truly serve this mission.

Conclusion

In addition to understanding access to preventive sexual health care for MSM, the study's purpose was intended to investigate the ways in which gaps to accessing PrEP have been experienced and continue to be experienced by MSM. Preventive sexual health care was being defined in the Facebook group in a particular way which afforded some MSM more ability to navigate a complex health care system that complicates how one is actually able to receive health care services, if at all, despite the fact that PrEP is marketed to all MSM and encouraged by the CDC as the one recommended pharmaceutical technology that prevents HIV transmission in the majority of cases.

References

- Centers for Disease Control and Prevention. *HIV Surveillance Report, 2014*; vol. 26.
<http://www.cdc.gov/hiv/library/reports/surveillance/>. Published November 2015.
Accessed February 6, 2017.
- Centers for Disease Control and Prevention. *HIV Surveillance Report, 2015*; vol. 27.
<http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published
November 2016. Accessed February 6, 2017.
- Central Intelligence Agency. (2010). Country comparison: Internet users. *The World Factbook Online*. Retrieved from <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2153rank.html>
- Conrad, P. (1992). "Medicalization and Social Control." *Annual Review of Sociology* 18:209-32.
- Conrad, P., & Leiter, V. (2004). Medicalization, Markets and Consumers. *Journal of Health and Social Behavior*, 45, 158-176. Retrieved from <http://www.jstor.org/stable/3653830>
- Conrad, P., & Leiter, V. (2008). From Lydia Pinkham to Queen Levitra: direct-to-consumer advertising and medicalisation. *Sociology of health & illness*, 30(6), 825-838.
- Crath, R., & Rangel, C. (2017). Paradoxes of an assimilation politics: media production of gay male belonging in the Canadian 'vital public' from the tainted blood scandal to the present. *Culture, health & sexuality*, 19(7), 796-810.

- Daniels, N. (1982). Equity of Access to Health Care: Some Conceptual and Ethical Issues. *The Milbank Memorial Fund Quarterly. Health and Society*, 60(1), 51-81.
doi:10.2307/3349700
- Donabedian A. The quality of care: how can it be assessed? *JAMA* 1988; 260(12): 1743-1748.
- Visnjic A, Velickovic V, Jovic S. Measures for improving the quality of health care. *Scientific Journal of the Faculty of Medicine in Nis* 2012; 29(2): 53-58.
- Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology, & Human Values*, 20(4), 408-437.
- Fairclough, N. (2013). *Critical discourse analysis: The critical study of language*. Routledge.
- Felder, S., & Mayrhofer, T. (2017). *Medical Decision Making*. [electronic resource] : A Health Economic Primer. Berlin, Heidelberg : Springer Berlin Heidelberg : Imprint: Springer, 2017.
- Fuchs C (2014) *Social Media: A Critical Introduction*. London: SAGE. [11 SEP]
- Kippax, S., & Stephenson, N. (2016). *Socialising the Biomedical Turn in HIV Prevention*. London, UK; New York, NY, USA: Anthem Press. Retrieved from <http://www.jstor.org/Stable/j.ctt1ffjq5g>
- Krakower DS, Mimiaga MJ, Rosenberger JG, et al. Limited awareness and low immediate uptake of pre-exposure pro- phylaxis among men who have sex with men using an In- ternet social networking site. *PloS One* 2012;7:e33119. [11 SEP]
- Levesque JF, Harris MF, Russell G. Patient-centred access to health care:

- conceptualising access at the interface of health systems and populations. *Int J Equity Health*. 2013;12:16–28.
- Mele, P. & Fuertes, J. N. (2017, May). Article summary: Racial bias related to lack of access to healthcare. [Web article]. Retrieved from: <http://societyforpsychotherapy.org/racial-bias-access-healthcare>
- Rangel, C., and B. Adam. 2014. “Everyday Moral Reasoning in the Governmentality of HIV Risk.” *Sociology of Health and Illness* 36 (1): 60–74.
- Wachter, R. M. (1992). AIDS, activism, and the politics of health.